

TIPS:

A New Diagnosis

Learning that your child has complicated health problems and ongoing medical needs can be overwhelming. You may feel alone and unable to cope with the wide range of emotions and new responsibilities brought about by your child's diagnosis. While no one else can fully understand all that you are going through, many other families have been in similar situations and have offered the following advice.

Caring for a child with complicated needs can be emotionally draining. At times you may feel sad, angry, guilty, defeated and it feels as if nothing can go right. Other times you will feel happy, proud, relieved, triumphant as you enjoy every little success your child has. It is important to acknowledge whatever you are feeling each day. Find someone you trust to talk with so you can work through your emotions. Remember to take time for yourself and your family, and you will be better able to care for your child with special needs.

Ensuring that your child's and family's needs are met may be overwhelming at first. Different professionals and programs are available to help you. Families in similar situations have shared different ways they have used to get through this difficult time. We hope their suggestions are helpful to you.

The health care team works with you to meet your child's needs

- ☐ Get to know each member by name.
- ☐ Learn what each one does.
- ☐ Learn how they work together with you.
- ☐ Establish good communication with them.
- ☐ Be open and honest about your needs.
- ☐ Ask questions.
- ☐ Identify the other providers who will work with your child.
- ☐ Identify who will make sure that your child gets the necessary care when going home from the hospital.
- ☐ Identify who will help link you to school and community services.
- ☐ Identify who will help you in planning for your child's long term needs.

It is important to organize your child's health information

- ⇒ Keeping your own records can be helpful in various ways. These can be shared with different members of the health care team, school personnel or other caregivers and can be used as verification when needed.
- ⇒ Keep a written record of medical and financial information about your child's care.
- ⇒ Copy important papers including doctors' bills, receipts submitted for reimbursement, applications for insurance and other services, and medical and educational summaries.
- ⇒ Keep these in a place where you can find them quickly.

Caring for your child will take time

- Decide how your routine needs to change to help you meet your new responsibility.
- Talk to other parents who have been through similar experiences.
- Learn about parent to parent support programs.
- Call the number below for information. All of the questions you have are important and need an answer.

Remember: although you may not know all the medical terms, you know your child best!